



## *Care Coordination Across the Continuum*

A WHCoA Solutions Forum

July 19, 2005  
9:00 a.m. – 12:00 noon

Russell Senate Office Building, Room 385  
Washington, DC





# Coalition for the Continuum of Care

Conveners of a White House Conference on Aging Solutions Forum



## Care Coordination Across the Continuum

The Care Coordination Coalition extends sincere thanks to Senator Herb Kohl (D-WI) and his staff for sponsoring the use of Russell Senate Office Building, Room 385, Washington, DC to convene this White House Conference on Aging Solutions Forum, *Care Coordination across the Continuum*, held July 19, 2005.

We also gratefully acknowledge the following organizations for their generous support and help in sponsoring this event

**The RAND Corporation** is a nonprofit research organization providing objective analysis and effective solutions that address the challenges facing the public and private sectors around the world.

**The Kaiser Permanente Community Benefit Fund** is a non-profit, private operating foundation focusing on the major health care issues facing the nation. It is an independent voice and source of facts and analysis for policymakers, the media, the health care community, and the general public.

**excelleRx, Inc.** is a technology-based medication management, consultation, and distribution company for palliative care and the frail elderly. Combining proprietary technology and clinical experience, excelleRx ensures the appropriate use of medication and thereby enhances quality of life.

**Department of Veterans Affairs, Geriatrics and Extended Care Strategic Healthcare Group** advances quality care for aging and chronically ill veterans by providing policy direction for the development, coordination, and integration of geriatrics and long-term care clinical programs.

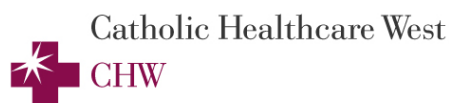
**Archstone Foundation** is a private grantmaking organization, whose mission is to contribute towards the preparation of society in meeting the needs of an aging population.

**The Atlantic Philanthropies** are a group of Bermuda-based charitable foundations whose grant investments are focused internationally in four programme fields: Ageing, Disadvantaged Children and Youth, Population Health and Reconciliation and Human Rights.

**Catholic Healthcare West (CHW)**, headquartered in San Francisco, Calif., is a system of 40 hospitals and medical centers in California, Arizona and Nevada. We are committed to delivering compassionate, high-quality, affordable health care services in a compassionate environment that is attuned to every patient's physical, mental and spiritual needs.

### Individual Support

The fifteen speakers and the additional planning committee members contributed their time without compensation to prepare and participate in the Solutions Forum.





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## Agenda



## AGENDA

July 19, 2005      9 a.m. –12:30 p.m.  
Russell Senate Office Building, Rm#385, Washington, DC

**Opening Remarks:**  
**Chair, WHCoA Policy Committee**

The Honorable Dorcas R. Hardy,  
President  
Dorcas R. Hardy and Associates  
Washington, DC

**Introductions and Overview: Solutions  
Forum Moderator**

Joanne Lynn, MD, MA, MS, Senior  
Natural Scientist, Palliative Care  
Policy Center, RAND, Arlington, VA

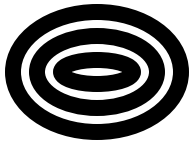
**Panel #1 – Envisioning Reliable and  
Sustainable Care for the Elderly Who  
Need it Most**

**Panelists:**

- Richard Bringewatt, President,  
National Health Policy Group,  
Washington, DC
- Katie Maslow, MSW, Associate  
Director for Quality Care  
Advocacy, Alzheimer's  
Association, Washington, DC
- Brian Duke, MHA, MBE, Director  
WHYY Caring Community,  
WHYY Wider Horizons,  
Philadelphia, PA
- Brian Hofland, PhD, Director,  
Aging Programs, Atlantic  
Philanthropies Aging Program,  
New York, NY

**Q & A**

WHCoA Policy Committee Members  
and comments from the public



# Coalition for the Continuum of Care

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### Panel #2 – Restructuring Services

#### Panelists:

- Thomas Edes, MD, Chief, Home and Community-Based Care, Department of Veterans Affairs, Washington, DC
- Richard Della Penna, MD, Director, Kaiser Permanente Aging Network, The Permanente Federation, Oakland, CA
- Carol Raphael, MPA, President and CEO, Visiting Nurse Service of New York, New York, NY
- True Ryndes, ANP, MPH, President and CEO, National Hospice Work Group, San Diego, CA
- Susan Tolle, MD, Professor of Medicine, Oregon Health Science University, Portland, OR
- Gerard Anderson, PhD, Professor of Health Policy and Management and International Health John Hopkins School of Hygiene, Baltimore, MD

### Q & A

WHCoA Policy Committee Members  
and comments from the public





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### **Panel #3 – Motivating Change – Information and Advocacy**

#### **Panelists:**

- J. Donald Schumacher, PsyD, President and CEO, National Hospice and Palliative Care Organization, Alexandria, VA
- Joseph Prevratil, JD, President and CEO, Archstone Foundation, Long Beach, CA
- Judith Black, MD, Medical Director for Senior Products, Highmark Blue Cross/Blue Shield, Pittsburgh, PA
- Anne Wilkinson, PhD, Senior Social/Behavioral Scientist, Palliative Care Policy Center, RAND, Arlington, VA

### **Q & A**

WHCoA Policy Committee Members  
and comments from the public

### **Conference Reporter**

Jon Fuller, MD, Deputy ACOS for Geriatrics & Extended Care, VA Palo Alto Health Care System, Palo Alto, CA

### **Q & A**

WHCoA Policy Committee Members  
and comments from the public

### **Closing Remarks**

Joanne Lynn, MD

### **Lunch**



Panel 1  
Envisioning Reliable and Sustainable Care for the Elderly Who  
Need it Most

Richard J. Bringewatt.....	7
Katie Maslow, MSW .....	11
Brian M Duke, MHA, MBE .....	15
Brian F. Hofland, Ph.D.....	19



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While most health care professionals recognize the importance of care coordination to improving care outcomes for high-risk patients, they frequently use different words to mean the same thing and the same word to mean different things. ‘Care management,’ ‘case management,’ and ‘care coordination’ are frequently used interchangeably. Consider the different focus associated with various provider groups.

1. Physician-based programs frequently focus on the *medical complexities* of a patient’s problem, with limited regard for psychological, social, or environmental concerns.
2. Social work models focus heavily on helping people access an array of *non-medical services*, often as an alternative to nursing home care, and frequently with minimal attention to related medical issues.
3. Hospital-based programs often focus on moving a patient through a *critical pathway* and expediting *hospital discharge*, without regard for the need to work in concert with other providers in the community to improve total quality and cost outcomes.
4. Disease management strategies often give primary attention to helping people with *self-care capabilities* adopt *evidence-based guidelines* for a specific, chronic condition. While they recognize the presence of co-morbid illness, they are limited in their ability to deal with the complexities involved in serving those with serious and disabling chronic conditions who cannot be easily self-monitored or require close provider collaboration
5. Managed care programs frequently give primary attention to controlling *benefit utilization* and may or may not address the complexities of multi-conditions that need tight coordination among multiple providers.

People with serious and disabling conditions, such as complex diabetes, congestive heart failure, COPD, and Alzheimer’s disease, are health care’s highest-cost and fastest-growing service group. Unfortunately, the nature of health care today is fundamentally inconsistent with their volatile, complex, interdependent, and ongoing care needs. To improve cost and quality outcomes across the continuum, health policy leaders must integrate their policies and financing methods just as the care of people with serious and disabling conditions must be integrated. Home health agencies, area agencies on aging, hospitals, physicians, nurses, social workers, pharmacies, long-term care providers, managed care, supplemental and long-term care insurance companies, corporate retirement programs—all purchasers, payers, providers, consumers, and caregivers involved in the ongoing care of people with multiple, complex, chronic conditions—must appreciate their interdependence and break through the financial, regulatory, structural, and cultural barriers that impede our ability to improve *total* quality and cost outcomes.

Coordinated care policy must recognize four realities:

1. **Care coordination is primarily for people with multiple, complex chronic conditions**  
Organizing care coordination around a single chronic illness ignores reality. Sixty-eight

percent of Medicare spending is for the 20 percent of beneficiaries with five or more chronic conditions.<sup>1</sup> People with five or more chronic conditions have an average of almost 15 physician visits, fill over 50 prescriptions a year, and frequently receive care from an array of health and social service providers. Thirty-one percent of this population is hospitalized each year, with the average cost of hospitalization dramatically rising in relation to a patient's number of chronic conditions. More than half of people with serious chronic conditions see three or more different physicians and many see other health and social service providers who seemingly don't talk with one another.<sup>2</sup> The frail elderly, those with cognitive impairments, persons with complex medical conditions, adults with disabilities, and people at the end of life are all adversely affected by our fragmented approach.

**2. Current health care policies and financing reward plans and providers for avoiding people with complex chronic conditions**

Hospital surgical and cardiac units are habitually more financially viable than medical units that offer more care for people with multiple, complex medical problems. Cardiologists, surgeons, and other high-tech medicine physicians are paid significantly more than internists, geriatricians, and family-practice physicians who specialize in caring for older patients with complex, chronic illnesses. In spite of the emergence of Medicare risk-adjusted financing, managed care plans that exclusively or disproportionately serve high-risk patients are adversely affected by a payment method that underpays medical assistance plans (in relation to fee-for-service financing) for their highest-cost enrollees and overpays them for their lowest cost enrollees. Long-term care providers also experience adverse incentives for serving people with more complex medical, social and behavioral problems. Care of those with complex chronic conditions must be supported by fair and sound business practices.

**3. We pay for separate and discrete units of service, days of care, and treatment methods without regard for their cumulative effects on total quality and cost performance**

Under current payment methods, each provider is paid to manage care within the walls of their own care setting, discounting the effects on *total* cost and quality performance. We generally ignore the pervasive presence of co-morbid illnesses; the relationship among disease, disability, and frailty; and the relationship of disease to a patient's mental and emotional state, functional ability, social relationships, and environment. We organize care as if providers are merely an array of unrelated parts shops, with separate and unrelated health care specialists dispensing doses as well as days of goods and services.

We develop separate and inconsistent financing and oversight requirements for Medicare and Medicaid, without regard for more than \$200 billion of annual expenditures for people dually eligible for both programs. We test and approve drugs without regard for the presence of co-morbidities or the affects of poly-pharmacy. We develop quality measures and reporting requirements as if related chronic care interventions have no relationship with one another. We know that adverse drug events, medical errors, and consumer

<sup>1</sup> Partnership for Solutions, Medicare Expenditure Panel Survey, 2001, *Chronic Conditions: Making the Case for Ongoing Care*, September 2004.

<sup>2</sup> Ibid, Partnership for Solutions.

anxiety are pervasive and significantly related to fragmented financing and care, yet nearly everyone continues to sub-optimize cost and quality without regard for significant and unnecessary confusion, medical complications, and costs *caused* by system fragmentation. Even managed-care companies tend to micro-manage payment and oversight for discrete products and services rather than longitudinally manage cost and quality for complex care.

4. ***There is increased evidence that our fragmented approach actually causes significant and unnecessary stress, confusion, medical complications, and costs***

People with multiple chronic conditions have different clinical needs, experience a more rapid decline in health status and disability, and are more susceptible to under-care or inappropriate treatment.<sup>3</sup> Among people with serious chronic conditions, almost half report they do not receive adequate treatment. Drug-to-drug interactions are common. About 45% of people with serious chronic conditions report that they receive conflicting advice.<sup>4</sup> People with four or more chronic conditions have a 99-time greater probability of being hospitalized for an ambulatory-care sensitive, chronic condition that could have been prevented with proper outpatient care.<sup>5</sup> The number of people who have a horror story about problems encountered in managing care for their mom or dad, sister or brother, neighbor or friend is astounding, yet nothing is done to fundamentally change the underlying way we manage care across the continuum.

To improve care coordination across the continuum, health policy leaders must:

1. ***Develop a person-centered, longitudinal, system-wide approach*** that is tailored to the unique needs and interests of people with serious and disabling chronic conditions. This approach must enable primary, acute, and long-term care providers who serve the same person, either at the same time or in sequence to one another, to use a common medical record, compatible clinical interventions, and simplified transition procedures. This will:
  - a. Reduce the frustrations of consumers receiving care from multiple providers.
  - b. Minimize medical errors, medical complications, and iatrogenic illness.
  - c. Enable consumers and purchasers to reduce unnecessary cost accumulation *caused* by antiquated and inappropriate health care financing and policy.
2. ***Eliminate administrative, financing, and regulatory barriers that impede the ability of plans and providers to develop a person-centered, longitudinal system-wide approach to care.*** The following low-cost/high-impact policy solutions should be considered for improving the coordination of care across the continuum:
  - a. Eliminate financial incentives for plans and providers to avoid complex care patients by fully risk-adjusting capitation rates and fee-for-service payments, with pay-for-performance rewards for specialized-care programs that enable clinical teams to stay with a patient and their family caregiver(s) as their needs change and

<sup>3</sup> Heather Young. 2003. "Challenges and Solutions for Care of Frail Older Adults." Online Journal of Issues in Nursing. Vol. 8. No. 2. Manuscript 4. May 31, 2003.

<sup>4</sup> Ibid. Partnership for Solutions.

<sup>5</sup> Wolff, Jennifer L., MHS, Barbara Starfield, MD, MPH, Gerald Anderson, PhD, "Prevalence, Expenditures, and Complications of Multiple Chronic Conditions in the Elderly, Archives of Internal Medicine, Vol. 162. Nov. 11, 2002.

to modify care plans in relation to a person's volatile, complex, and ongoing chronic condition.

- b. Eliminate the concept of 'discharge planning' and establish 'transitional care planning' policy to improve patient safety, efficiency, and performance in care transitions.
- c. Standardize data collection and care planning requirements and support information systems development among network providers to enable use of common medical records and compatible clinical interventions for complex care patients.
- d. Develop improved payment methods and simplify oversight for *principal care* physicians who see a high percentage of patients with complex chronic care needs.
- e. Develop care network certification methods and establish collective performance incentives to improve interdisciplinary and inter-program capabilities.
- f. Establish new quality measures for complex chronic conditions to more fully account for co-morbid illnesses, frailty and/or disability, and multi-provider involvement.
- g. Require drug companies to test drugs, before they go to market, for their potential to produce adverse drug events where the drug is likely to be used in combination with other drugs for patients with multiple chronic conditions.
- h. Eliminate adverse incentives, administrative inefficiencies and regulatory conflicts in serving persons dully eligible for Medicare and Medicaid to enable purchasers, plans, and providers to optimize *total* cost and quality outcomes.
- i. Create incentives for supplemental insurance and long-term care insurance companies to establish compatible primary, acute, and long-term care benefits and financing policies.
- j. Require monitoring of longitudinal costs and quality for high-risk chronic conditions.
- k. Empower consumers and family caregivers with self-help information, skills training, back-up consultation, and peer-to-peer support so that they can better manage their complex care needs.

To date, most care coordination initiatives have been established more out of a sense of social commitment to do what is right than because it is "good business." They have been developed within the context of isolated programs or add-on functions that leave in place a maze of disconnected services that cause significant and unnecessary stress, confusion, medical complications, and cost. People with multiple, complex chronic conditions are healthcare's highest-cost and fastest growing service group. The time to fix the problem of care fragmentation is now.



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At least 4.5 million elderly Americans have dementia caused by Alzheimer's disease, vascular disease, and other conditions.<sup>1</sup> Almost half of all nursing home residents and 40-60% of assisted living residents have dementia.<sup>2,3,4</sup> Half of all elderly people in adult day centers have dementia,<sup>5</sup> and many people with dementia and their families use other services that are available in our non-system of home and community-based care. Many do not use services that would help them because they are not aware of available services and do not know how to find them.

Families of people with dementia, on average, provide more physically and emotionally demanding care than families of other elderly people and adults with disabilities; they provide more hours of care a week; and they provide this care for a long time.<sup>6</sup> Many of them report high levels of stress and depression.

These ideas are well known.

Now we also know that elderly people with dementia are three-times more likely to be hospitalized than other elderly people and 2.4 times more likely to be hospitalized for an ambulatory-care sensitive condition.<sup>7 8</sup> Many people with dementia have other serious illnesses; for example, 28% have congestive heart failure, and 21% have diabetes. Most often, they are hospitalized because of these other illnesses,<sup>9</sup> however, their dementia complicates their care and often results in difficult hospital stays and poor short and long-term outcomes. Then they are discharged back to the non-system of community care and family caregivers who are often

1. Hebert LE, Scherr PA, Bienias JL, et al. Alzheimer's Disease in the US Population: Prevalence Estimates Using the 2000 Census. *Archives of Neurology* 2003;60:1119-1122.

2. U.S. Centers for Medicare and Medicaid Services, *CMS OSCAR Data Current Surveys, June 2005: Medical Condition – Mental Status*, downloaded July 12, 2005.

[http://www.ahca.org/research/oscar/rpt\\_MC\\_mental\\_status\\_200506.pdf](http://www.ahca.org/research/oscar/rpt_MC_mental_status_200506.pdf).

<sup>3</sup> Sloane PD, Zimmerman S, and Ory MG. Care for Persons With Dementia. *Assisted Living: Needs, Practices, and Policies in Residential Care for the Elderly*, S Zimmerman, PD Sloane, and JK Eckert (eds) (Baltimore, MD: Johns Hopkins University Press, 2001) pps. 242-270.

<sup>4</sup> Rosenblatt A, Samus QM, Steele CD, et al. The Maryland Assisted Living Study: Prevalence, Recognition, and Treatment of Dementia and Other Psychiatric Disorders in the Assisted Living Population of Central Maryland. *Journal of the American Geriatrics Society*, 52(10):1618-1625, 2004

<sup>5</sup> Cox N, Starke M, and Holmes C. *National Study of Adult Day Services: Key Findings 2001-2002*. (Winston Salem, NC: Wake Forest University School of Medicine, 2002).

<sup>6</sup> Alzheimer's Association and National Alliance for Caregiving. *Families Care: Alzheimer's Caregiving in the United States: 2004* (Washington DC: Alzheimer's Association, 2004).

<sup>7</sup> Ambulatory-care sensitive conditions are conditions that can be prevented altogether or whose course can be mitigated through optimal outpatient management, thereby preventing hospitalization.

<sup>8</sup> Bynum JPW, Rabins PV, Weller W, Niefeld M, Anderson GF, and Wu AW. The Relationship Between a Dementia Diagnosis, Chronic Illness, Medicare Expenditures, and Hospital Use. *Journal of the American Geriatrics Society*. 52(2):187-194, 2004.

<sup>9</sup> Medicare data show that that dementia increases the likelihood of hospitalization for elderly people with illnesses, such as congestive heart failure and diabetes, and conversely, these illnesses increase the likelihood of hospitalization for elderly people with dementia.

overwhelmed by post-acute care needs that are added to the person's ongoing ADL and IADL care needs.<sup>10</sup>

High use of hospital care creates high costs for Medicare. In 1999, total Medicare expenditures for people with dementia were 3.3 times higher than for other elderly people, and hospital care accounted for half the total.<sup>7</sup> The greater likelihood of hospitalizations for ambulatory-care sensitive conditions\* suggests that better care management might reduce the total number of hospitalizations, decrease Medicare expenditures, and most importantly, avoid the difficult inpatient experiences and poor outcomes associated with hospitalization for people with dementia.

The care needs of people with dementia clearly cross the continuum, and their dementia makes them highly vulnerable to uncoordinated care. They need comprehensive, systematic care coordination that:

- Addresses the whole person, not just his or her dementia, CHF, diabetes, or other acute or chronic condition;
- Makes information about the person's cognitive status and medical and nonmedical care needs available to all his or her medical and community care providers; people with dementia generally cannot provide this information themselves, so it must be accessible whenever and wherever they receive care;
- Provides multidisciplinary care planning that incorporates awareness of the person's cognitive status and its implications for his or her care;
- Involves the person's primary care physician and coordinates medical care provided by all his or her other physicians health care providers;
- Links medical care and supportive community services; and
- Identifies, involves, and supports family caregivers.

Family caregivers cannot be an afterthought. They provide most of the care for most people with dementia. Comprehensive care coordination that is built in – not added on -- to medical and community care must have routine procedures for connecting with family caregivers, giving them the information they need to care for their relative, and responding quickly to caregiving crises that arise, for example, because of new cognitive, psychiatric, or behavioral symptoms.

Comprehensive care coordination must also establish procedures and responsibility for transitions between care settings. Such transitions are frequent and often difficult for people with dementia and their families. The usual discharge planning process is not sufficient. The care coordination system must assure that the transition works, not just that it happens.

We know a lot about how to deliver comprehensive care coordination that works for people with dementia. Over the past eight years, the Alzheimer's Association has funded and participated in numerous demonstration projects to test ways of coordinating medical and supportive community services for people with dementia. We have worked primarily with Medicare managed care

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<sup>10</sup> Naylor MD, Stephens C, Bowles KH, and Bixby MB. Cognitively Impaired Older Adults: From Hospital to Home. *American Journal of Nursing*. 105(2):52-61, 2005.

organizations because capitated payment creates both flexibility to try new approaches and financial incentives to reduce unnecessary use of high-cost hospital care. The results of these demonstration projects are encouraging. Findings from our demonstration project with Kaiser Permanente in Cleveland show statistically significant positive psychosocial outcomes (reduced depression and strain for family caregivers and reduced feelings of shame and isolation and greater ease of coping for people with dementia). The findings also show statistically significant reduction in use of hospital and emergency room care for a subset of patients (those whose memory problems worsened over the one-year period of the study).<sup>11</sup>

We have similar findings from our 6-site demonstration project, *Chronic Care Networks for Alzheimer's Disease (CCN/AD)*. In this project, Alzheimer's Association chapters worked with managed care organizations and a large VA health care network to increase coordination of medical care and supportive community services. Over three years, more than 1,500 people with dementia and 1,450 family caregivers were enrolled. Health care professionals and chapter staff reported positive attitudes about the working partnerships that developed between their organizations. People with dementia and their families reported high levels of satisfaction and reduced depression and strain.<sup>12</sup>

The best results were achieved in the site that had the most extensive care coordination. In the CCN/AD site in Denver, the local Alzheimer's Association chapter and a capitated physician practice group developed a common care plan for their project enrollees and emailed the care plan back and forth as each organization worked to achieve the care plan objectives for the person and family. People with dementia and family caregivers at this site reported a very high level of satisfaction. Of course, the project could not change the dementia, but people with dementia and their families reported that they received enough help and their needs were met.

The Cleveland and CCN/AD projects were feasible, that is, they could be implemented, in capitated health care systems. We need reimbursement and payment policies that make it financially plausible for all physicians and other health care professionals to provide coordinated care. In all our dementia demonstration projects, changing care practices also required leadership, encouragement, training, and time. To be effective, a new system of coordinated care will have to create, plan for, and reward these additional prerequisites for change.

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<sup>11</sup> Bass DM, Clark PA, Looman WJ, McCarthy CA, and Eckert S. The Cleveland Alzheimer's Managed Care Demonstration: Outcomes After 12 Months of Implementation. *Gerontologist*. 43(1):73-85, 2003; and Clark PA, Bass DM, Looman, WJ, McCarthy CA, and Eckert S. Outcomes for Patients with Dementia from the Cleveland Alzheimer's Managed Care Demonstration. *Aging & Mental Health*. 8(1):40-51, 2004.

<sup>12</sup> Findings from the CCN/AD project as a whole have not yet been published. Findings from the upstate New York site where four Alzheimer's Association chapters worked with a large VA health care network (VISN 2) are available in print or pdf format from the Alzheimer's Association.



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The Honorable Dorcas Hardy, Members of the White House Conference On Aging Policy Committee, Honorable Members of Congress, Fellow Panelists, Colleagues, and Participants:

First, allow me to express my thanks for the opportunity to join today's presentation of solutions to the challenges faced in coordinating care across an ever-growing continuum. My voice today is united with the voices of fellow caregivers and with the leading national organizations dedicated to researching, implementing, and advocating the changes necessary to ensure support of the caregiver in our communities.

That is what I think the solutions we need to consider are all about: uniting voices and building community. It has been said that caregiving is likened to a journey. Over time, in anticipation of the White House Conference on Aging, you have heard of this journey in ways that have defined the problems, the statistical profiles, the burdens, and the need for change in both policy and practice. I believe that this journey begins at the bedside in homes across our country, and it is from that starting point that I would like to offer solutions that will enhance caregiving within existing care continuums.

First, we need to adopt a uniform system of caregiver assessment. This assessment must be required during intake, first visit, or admission protocols. Reimbursement for this assessment should be included in the profile of allowable charges for Medicare. The assessment must be uniform as stated, but it also must provide meaningful data to help us know what the caregiver needs and how their health and well-being are as they enter into and progress along their journey. The assessment must also be manageable. There are outstanding examples of assessments available for possible use. We need to make sure that the implementation of the assessment does not place undue burden on the caregiver or on the staff, whose duties have often been constricted by changes in reimbursement. Data from this assessment, which is uniform, meaningful, and manageable, will inform the continuum of providers about caregiver needs.

Second, one-point systems of access to information and referral services should be replicated across the country. The New Jersey EASE system is one example of a single point of entry. This model should be adapted to local needs and adopted across the country. It allows for a caregiver to search for information by local county, uses search language that is comprehensible, and identifies at the very least an initial point of contact. Funding to the National Family Caregiver Support Program should be provided to continue the growth of one point of access systems.

Third, a care navigation system needs to be created for the caregiver. Care navigation begins with comprehensive discharge planning and accompanies the caregiver as they accompany the care recipient along the many different types of services along the continuum. There is a need for an information system that accompanies the patient and caregiver so that duplicative processes are eliminated and errors attributed to medication and care management are reduced. The system needs to be able to be accessed from all points along the continuum, be knowledgeable about care options in a given community (both public and private), be aware of systems of referral, and be sensitive to the needs of the caregiver of persons with acute, chronic and terminal illness.

Building blocks of best practice for a care navigation system may include the clinical team-based practices of geriatric or rehabilitation medicine, geriatric care managers, and advanced primary care nursing practices. Navigation begins with clearly identified needs (assessment), translates existing service options so they are understood, facilitates access to care and maintains contact with caregivers throughout their journey. Some of the building blocks are available now on a fee for service basis that could raise economic barriers for some individuals. A call for demonstration models should mandate the requirement to include an economic model that allows access to as many persons as possible. Perhaps the recently passed Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 has concepts that could contribute to a navigation system that encompasses both care recipient and caregiver. A care navigation system is and will be a necessity to fulfill deficits created by current managed care and discharge planning systems. Funding should be provided to the US Department of Health and Human Services to provide grant funding for effective and inclusive care navigation demonstration projects.

Fourth, community-based collaborative efforts, coalitions, or partnerships must continue to grow. Funding and incentives should be provided for the creation of local demonstration projects that mandate public/private collaboration, invite the business community to the table, and mandate action toward sustainability at the local level. These collaborative community based efforts will lead to a more comprehensive definition of caregiver need as they navigate systems of care, provide an inventory existing services, enhance access, and begin the important process of planning for a future of caring. This future will mandate a community-based response as we encounter changing family demographics and shifts in the number and type of health professions available. It also in this fourth solution that we will find solutions developed that support changes in community norms. The care of the ill and injured is not the responsibility of any one individual or entity in our communities. The caregiver's journey does not take place at a national or state level; it takes place in the local community. The care of our sick, injured or disabled will require the collaboration of individuals, organizations, government, the business community, faith-based organizations and the many other living components of our American communities. Increased funding should be allocated to the US Administration on Aging; National Family Caregiver

Support Program to support the replication of successful community-based collaborative efforts as well as the development of new efforts.

The journey of every caregiver begins at the bedside and continues in the local community. These solutions grow from the spoken and unspoken needs and expectations of the caregiver. The solutions assess need, simplify access, navigate care systems and support the building of communities supportive of caregivers. Some of these changes may be viewed as simplistic, descriptive of dream-like states, or nostalgic. I believe they indicate a reality fast approaching that will truly support the caregiver.

I thank you for your time and look forward to questions at the appropriate time on today's agenda.





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### **Reliable and Sustainable Care for the Elderly Who Need it Most**

Older adults who are unable to do their activities of daily living rely upon health care, supportive housing, and other services being readily available and well-coordinated. At this time of life, living reasonably well requires a functionally seamless continuum of care in hospital, rehabilitation, nursing home, community-based (e.g., adult day care, caregiver support groups), and home care settings. Unfortunately, health policy, planning, and research have not attended to these individuals, and services at home and in long-term facilities have long been the poor relations of medical treatment and hospital care.

The reasons underlying this neglect include the following:

- The habit patterns of care providers that do not readily adjust to the changing demographics of the aging population
- Cultural ageism that denies the realities of aging itself and that ascribes a low status to long term chronic and supportive care
- Lack of knowledge of policymakers, care providers, and consumers
- Fragmentation of funding streams that sustains fragmentation of services and systems of care
- Under-funding of long-term chronic care, since reimbursement drives the focus of attention in health care delivery, research, and policy

Fortunately, a number of promising and practical models offer solutions to boldly chart the way for a brighter future regarding the care we will need as older adults with chronic care conditions. These include:

**PACE (Program of All-Inclusive Care for the Elderly).** The PACE program is a capitated managed-care benefit, authorized by the Balanced Budget Act of 1997, for frail elderly that features a comprehensive medical and social service delivery system. The benefit integrates Medicare and Medicaid financing, and the program is at-risk for all costs of care including housing and medications. PACE uses a multidisciplinary team approach in an adult day health center, supplemented by in-home and referral service in accordance with participants' needs. PACE is centered on the premise that the well-being of older adults with chronic care needs requires care in the community whenever possible. PACE has grown slowly, but evaluations and reputation show high quality and patient and family satisfaction.

**Evercare.** Evercare, a business unit of UnitedHealth Group, provides medical services to long-stay nursing home patients. Its capitated package of Medicare-covered services ensures more intensive primary care provided by nurse practitioners on-site, intended to supplement the medical care provided by physicians. Evercare works out financially because better primary care generally results in reduced hospital use. Moreover, Evercare strives to optimize the health and well-being of nursing home residents by providing comprehensive, customized care planning, care coordination, and care delivery onsite and in hospital for frail and chronically ill older people living in nursing homes. Evercare is at-risk only for the Medicare-covered services. Evaluations to date show uncertain savings, good quality outcomes, and some shift in costs to Medicaid because sicker people stay on-site in the nursing facility.

**Group Health Cooperative.** Group Health Cooperative is a consumer-governed, not-for-profit health care system based in Seattle, Washington that is now affiliated with the Kaiser Permanente system. Through its Center for Health Studies and the MacColl Institute for Healthcare Innovation, it has done some illuminating demonstrations involving collaboration with senior centers and the innovative use of older adult peer counselors to effectively transmit medical information to older adult consumers. These efforts have shown that older consumers most effectively learn health information from peers and will follow through with health regimens and prescribed care when there is periodic checking-in by, and technical assistance from, an informed and concerned peer and/or professional.

**Hospice.** More than 3,500 hospice programs throughout the country provide comfort and support to patients and their families when life-limiting illness no longer responds to cure-oriented treatments. Hospice care neither prolongs life nor hastens death, but offers a specialized knowledge of medical care, including pain and symptom management. Hospice care has shown that a patient's pain and discomfort can almost always be relieved and the patient made comfortable. Funded by the Medicare Hospice Benefit, which pays a set rate per day for each of four levels of service, hospice care is provided by a team of specially trained professionals, volunteers, and family members. Hospice is not a place, but a concept of care and an organized program of services. More than 80 percent of hospice care is provided in the patient's home, family member's home and in nursing homes. Inpatient hospice facilities or contracted beds in hospitals or nursing homes are available to assist with caregiving or to manage difficult symptoms. Many palliative-care lessons gained from hospice care could be fruitfully generalized to the care of non-terminally ill patients in hospital and nursing home settings, since some people live for many years with serious illness, as Rich Bringewatt, the first speaker in this panel, made clear.

The rapidly growing older population is not just a problem, but it is part of the solution. Eighty five percent of the 65+ population are essentially healthy and able-bodied. These individuals may

have a chronic condition, such as arthritis, but not have impairment of activities of daily living. Agencies responsible for innovation and research should be exploring and testing how relatively healthy and able-bodied older adults could provide services to seriously chronically ill older adults, both as volunteers and as paid caregivers. For society, this strategy could help solve the critical worker shortage in chronic care. Many older adults will find this volunteer activity to be a source of personal satisfaction and meaning. Other older adults who need to supplement their income could serve as paid caregivers.

As this panel's speakers have highlighted so strongly, chronic care for older adults is a problem that we absolutely have to tackle. Almost all of us will have many months, perhaps years, living with serious illness and disability at the end of life. At present, though, costs are remarkable, services are unreliable, families are distraught, and patients suffer avoidable injuries and symptoms. We have only a dozen years before the Baby Boomers will start to live with serious disabilities, and the current patchwork of services will simply be overwhelmed. We no longer have the luxuries of allowing a cultural lag between the demographic reality and our systems of care, of denying aging, and of treating chronic care as the stepchild of health care. We can, and must, build on the important promising models tested to date and aggressively supplement these with new and creative ideas. We need to use the next decade to learn how to provide a care system that we can count on, with an array of pilot programs, regional innovations, and an attitude of exploration and learning. We need to monitor how well we are doing across time and regions and to have a highly visible and reliable set of measures to guide us. Let us build an America in which we can all age and end our days with dignity and grace, relying on well-designed and sustainable health and support services that support very sick people from the onset of disability or illness through all of the rest of life.



**Panel 2**  
**Restructuring Services**

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I am privileged to be here to talk with you today about the Department of Veterans Affairs' remarkable successes in care for persons facing serious chronic illness. Although I will focus upon our Home-Based Primary Care program, or what we call HBPC, let me also mention that the VA has an array of dramatically effective initiatives in care for this population. We now have hospice and palliative care available in every VA medical center. A few years ago, we made advance planning a priority and showed that most of our patients facing serious chronic conditions could decide ahead about decision-makers, resuscitation, pain treatment, and other critical elements of care. Our electronic health record is an industry standard, and one of the few that include documentation of patient preferences for ready retrieval throughout the system. By many measures, veterans using VA services have a much more reliable care system for serious illness in their last years of life than do other Americans.

VA Home-Based Primary Care is a home care program that provides comprehensive, interdisciplinary, primary care in the homes of veterans with complex medical, social, and behavioral conditions for whom routine clinic-based care is not effective or not practical. My first objective is to show the differences between VA Home-Based Primary Care and Medicare or other conventional home care. My second objective is to share just how well Home-Based Primary Care fulfills a great unmet need – helping people with advanced, chronic, disabling conditions remain in their homes through home care that is comprehensive, interdisciplinary, and longitudinal - often for years.

VA Home-Based Primary Care is very different from Medicare home care; HBPC differs in the target population, in process, and in outcomes.

First let me address the population. VA Home-Based Primary Care targets individuals with complex, chronic disabling conditions, generally persons with conditions that gradually get worse rather than improve – conditions such as advanced heart failure, lung disease, diabetes, and neurologic disease. While Medicare home care was designed primarily for post-hospital care, and does very well for persons with short-term remediable conditions that get better within a few weeks, it does not cover the long-term home care needs of those with complex chronic disease.

VA Home Based Primary Care also follows a process that differs from Medicare home care. HBPC provides continuous, longitudinal home care rather than episodic care. HBPC is interdisciplinary, bringing in a team that includes a social worker, dietitian, rehabilitation therapist, nurse and physician, who meet regularly as a team and develop a care plan adapted to this particular patient and family. While Medicare home care is generally focused on a specific remediable problem, HBPC is comprehensive, addressing the multiple medical, behavioral, and social conditions faced by an individual patient. Unlike Medicare home care, HBPC does not

require a skilled need, strict homebound status, or improvement. HBPC is intended to be long term, providing continuous care for years, often through the end of life.

HBPC has another critical difference - the outcomes. First, our patients and families are delighted with the services. Many patients are left adrift by conventional home care because they do not improve, they do not have a skilled need, or their needs surpass the limitations in service scope and duration. Those constraints vanish in HBPC. Furthermore, in an analysis of 1 million Medicare home care patients and 3 million home care visits, Welch demonstrated no impact of Medicare home care on hospital days or total cost of care. In contrast, in a recent retrospective case-control national analysis of all VA Home-Based Primary Care patients, enrollment into HBPC was associated with a 62% reduction in hospital days, and a substantial reduction in emergency room visits and nursing home days. And although the cost of this interdisciplinary, longitudinal home care was nearly \$10,000 per patient per year, providing this comprehensive home care to this very sick population was associated with a net 24% reduction in total cost of care.

In summary, the VA Home-Based Primary Care program shows how to provide excellent and efficient care for persons with complex, chronic disabling disease. We succeed in helping them remain at home, maximize their independence, reduce avoidable hospital and nursing home days, and we do this at substantially lower cost. VA can do this because we provide comprehensive interdisciplinary care, coordinate care across all settings, and provide enduring rather than episodic care through a program designed for chronic disease, not bound by constraints designed for short-term problems. VA does this for 11,000 veterans every day, and I believe this model of care should be available for all Americans as they live with serious illness in old age.

#### References

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Edes T, Kendall S, Longitudinal Home Care for Chronic Disease, *J Amer Geriatr Soc.* 2005;53:s207.

#### Recommendations

1. Establish a pilot program within CMS to target persons with advanced disease and complex, chronic disabling conditions who are at high risk for hospitalization and nursing home care. Provide comprehensive, interdisciplinary longitudinal home care similar to the Home-Based Primary Care model in the Department of Veterans Affairs.
2. Make a web-based electronic medical record available for every American that can be immediately accessible by any health care provider, with patient authorization. Utilize the model of the electronic medical record system operating nationwide in the Department of Veterans Affairs.



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Kaiser Permanente's origins go back to the 1930's when it began as a prepaid group medical care program that provided for the work related and general health needs of industrialist Henry J. Kaiser's employees. Dr Sidney Garfield, founder of the first Permanente Medical Group, partnered with Mr. Kaiser in this effort, and after World War II, the Program opened its membership to the public. Today there are 8.3 million Kaiser Permanente members in nine states and the District of Columbia. Kaiser Permanente provides a high-quality, cost-efficient alternative to fee-for-service and network-managed care. Kaiser Permanente's prepaid group practice approach to care and its integration of finance and care delivery demonstrate that the way care is organized and the delivery system structure do matter. Mr. Kaiser and Dr. Garfield's original principles have shaped the Kaiser Permanente Program for close to 60 years. They have stimulated investment in quality, performance improvement, and innovative approaches to the changing care needs of our members.

Kaiser Permanente, because it is a prepaid integrated system, is able to do things others cannot, because of the framework and incentives under which they work. I regularly hear that what Kaiser Permanente is able to accomplish is not relevant or applicable to the much larger fee-for-service environment. My answer is that if what we do improves quality and is valued by beneficiaries and their families, then it is very relevant. The challenge is for others to figure out how they can achieve the same results. There are ongoing attempts and demonstrations to transfer to other models the successful approaches developed at Kaiser Permanente and other integrated care organizations.

Nine hundred and fifty thousand (950,000) Kaiser members are over age 65. Eighty thousand (80,000) of our members are over 80 years old, and 581 are centenarians. Many of these older adult members have serious, disabling illnesses that over time have or will diminish their ability to care for themselves and become reliant on caregivers and long term care for tasks small and large. Care requirements during the progression of these serious conditions change significantly and expand well beyond the borders of current benefits, traditional disease management and medical care. Meticulous treatment and care coordination for conditions like depression, cognitive impairment, incontinence, and immobility can enhance the quality of day to day living for people and families but repeated evaluations of current care across America tell us that these conditions are under recognized and under treated.

Longitudinal care for this population creates challenges to care continuity as people with advanced and serious illness typically have frequent contact with many physicians and multiple admissions to the hospital, home health agency, and skilled nursing facility and may undergo many diagnostic procedures and treatments. Having an awareness of the direction of care and meaningful participation in decision making are often absent. Kaiser Permanente's integrated system makes the solutions for some of these challenges more straightforward than other current finance and delivery approaches can usually achieve now.

### **Taking a population- and evidence-based approach**

Our Care Management Institute or CMI supports physicians in identifying and reaching out to members so they get the reliable evidence based medical care they need and want for their chronic conditions. The Care Management Institute's work includes populations with common conditions including diabetes, depression, chronic pain, cancer, and heart failure, as well as a population-based approach to the care of older adults, people with dementia, and those with advanced illness who are approaching the last years and months of life. CMI develops content, measures and trends performance in meeting essential steps in care, and promotes the uptake of successful and promising practices that make care more reliable and efficient. These efforts are important as they are aimed at modifying the course of conditions that lead to disability, distress, dependence and often death.

### **Investing in computerized records and support**

Computers are responsible for many of the amazing advances in care and also have contributed to complexity. Computers can help solve many of the challenges to longitudinal and chronic care. The paper medical record leads to inconsistencies in patient care and dysfunctional information transmission systems. It is an outmoded, ineffective support system for clinicians, patients and families. The current situation particularly affects people with serious chronic conditions. Kaiser Permanente currently is implementing HealthConnect, its computerized, patient-specific, integrated health record. HealthConnect has the potential to reengineer care. It will be available at all sites of care. On the clinician and delivery side, it has features that allow for structured documentation, prompts, alerts, and after visit summaries for patients. Patient directed goals for care will transcend current silos. The goal is to make care and information transmission more efficient, consistent, reliable, and safe. Members can access HealthConnect for making appointments, refilling medications, viewing their own information, getting information, and communicating with physicians. All members will benefit from this massive effort, but it will have special impact for people with serious chronic conditions. For example, we already keep

advance care plans electronically for many members, and this project will allow them to be integrated into the overall record and plan. Regional health information organizations have the potential for developing and building the electronic infrastructure to support improved care coordination among practitioners in the fee-for-service world.

### **Investing in new approaches to care**

In the Elder Care work at the Care Management Institute we reviewed the evidence of sustainable approaches to patient and family centered care for people with serious and advanced illnesses. There is strong consensus on what needs to be done, but the evidence was lacking on how to achieve this care in a sustainable way. So Kaiser Permanente strategically invested in a *Palliative Care Initiative* to increase our knowledge on how to meet many of the challenges this population faces in getting the care and services it needs over and above what traditional medical care provides. There have been two rapid cycle improvement collaboratives with over sixty teams from hospital, hospices, home health agencies, medical offices and emergency departments. These teams worked on improved advance care planning, symptom management, continuity and caregiver support. Kaiser Permanente also built and tested models for effectiveness and sustainability. The emphasis was on team approaches to better detect and treat distressful symptoms, improve clinician-patient communication, elicit patient and family preferences, set goals, enhance continuity, expand access, support caregivers and improve satisfaction. Patients and families in the home based program anytime day or night can reach a clinician, who knows them and, if need be, get a home visit.

Two randomized controlled trials have been completed a third based in physician offices is ongoing. The two completed studies have demonstrated positive and encouraging findings. Members in the Home Based Program had full access to traditional medical care but elected to follow a different service path and had significantly less physician and emergency department usage and fewer hospitalizations. Their satisfaction and symptom management were statistically improved over the control group. Their costs were 45% lower. We have also found that our patients were relieved that they and their families were able to talk with care team members about approaching life's end while still maintaining hope. We concluded that improvement in communication, continuity, patient-caregiver satisfaction, and distressing symptom management can be accomplished in a cost effective approach that is sustainable.

Why are these services sustainable? Because Kaiser Permanente has an integrated delivery system and the cost associated with hospitalization and physician office visits in conventional care can be shifted to the services in the community that many Kaiser Permanente patients want and prefer. These services are expanding to our membership across the Kaiser Permanente Program and we continue to search for new ways to meet the care needs of members with serious illness.

In closing, I want to emphasize that while this work is promising and encouraging, it remains fragile and subject to limits because much of it is not codified as a benefit. The current regulatory, reimbursement and benefit structure is biased towards expensive technologies that often do not benefit people with advanced illness but without opportunity for discussion too often become routine. There are limits to what Kaiser Permanente and other organizations can do to improve the current situation beyond what the traditional model. Uncertainty about future reimbursement and the requirement to provide mandated current and new benefits lead to constrained innovation and cautious expansion of new types services to other populations. Organizations that are successful in providing this highly valued organized care also face the risk of attracting very sick people without properly risk-adjusted reimbursement.

In conclusion I have two comments:

- Continue with the implementation of risk adjusted reimbursement with refinements to reflect the provision of high value, continuous longitudinal care to people with severe advanced illness, and
- Expand efforts to provide care coordination and to test that it will save health care dollars.

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Good Morning. I want to thank the White House Conference on Aging Policy Committee for the opportunity to speak on potential solutions that create a more cohesive healthcare system for those with serious and disabling chronic illnesses, particularly in home and community settings. In order to meet this priority and to avoid costly and sometimes unnecessary institutional placements, it is vital that this population have easy access to a variety of flexible medical and supportive services. I would like to highlight several promising models Visiting Nurse Service of New York (VNSNY) has implemented. These models could offer scalable solutions to address the fragmentation, avoidable costs, and difficulties experienced by this population in navigating the health care system.

VNSNY is unique in many ways. First, it provides a comprehensive array of round-the-clock, post-acute, rehabilitative, mental health, long-term care and end-of-life services to residents in the New York region. VNSNY has launched a number of innovative care models including a Congregate Care program, a Remote Physiological Monitoring program, a partially capitated Medicaid Managed Long Term Care Plan, long-term care waiver programs, a Program of All-inclusive Care of the Elderly (PACE), and palliative care services. Its Centers of Excellence focus on diabetes and wound care management, cardiopulmonary care, and AIDS treatment.

Second, VNSNY serves a multi-cultural patient population that speaks over 38 languages. Third, VNSNY works collaboratively with hospitals, nursing homes and community physicians not only to facilitate discharge and after care, but also in a number of new, collaborative ventures like a Home Visiting MD Program and a partnership with a hospital-based clinic where a VNSNY Advanced Nurse Practitioner-intermediary manages the care of hundreds of clinic patients in the community. Fourth, VNSNY care teams are focused on achieving the best possible outcomes. These may include improving functioning, avoiding adverse events, stabilizing a condition, preventing deterioration and ensuring quality of life. VNSNY has made major investments in building a quality infrastructure, one that not only measures outcomes but also processes of care, utilization, and the patient and family experience. Fifth, VNSNY is the only home care agency nationally that has an established Center for Home Care Policy and Research that conducts policy-relevant research on the management and quality of home and community-based services.

### **Solution 1: Expand Managed Care Options to Long-Term Care**

Managed long-term care plans focus on the high-cost, long-term care dually eligible population, while improving outcomes and reducing expenditures. Offering bundled long-term care services for the frail elderly in the community, these plans receive monthly Medicaid capitated payments per enrollee. While the capitated payment is for a bundle of long term care services, multi-disciplinary care teams coordinate acute and long-term care services across multiple providers. Care is focused on improving the quality of life for the enrollees by ensuring that, to the fullest extent possible, they can remain as independent as possible in their home and community.

VNS CHOICE, for example, is VNSNY's Medicaid-capitated managed long term care plan and has had many successes. It has 3,750 enrollees, many of whom have multiple chronic conditions. About 40% have four or more comorbidities and most take more than 10 medications daily. Through extensive care management within a wide network of 115 health and community providers, VNS CHOICE offers multiple benefits. In a recent evaluation<sup>1</sup>, the program decreased hospital admissions by 23% and decreased the average length of stay in a hospital by 18%. In one year, utilization of the emergency room and unplanned physician visits decreased by 30%. VNS CHOICE spends only 11% of its premium on nursing home expenditures while 67% is expended on a range of home and community-based care, 10% on medications and almost 2% on transportation expenditures. In a recent patient satisfaction survey, VNS CHOICE enrollees expressed considerable satisfaction with the services the plan offers.

### **Solution 2: Move Services Upstream to Facilitate Aging-in-Place for All Seniors:**

Models that focus on early detection have the capacity to prevent the onset of chronic conditions, as well as to reduce complications once they occur.

One innovative care model is the placement of a nurse at congregate care sites. At VNSNY, for example, clinicians are on-site at 214 congregate sites that include assisted living facilities, senior housing and Naturally Occurring Retirement Communities (or, NORCs). Nurses assess residents living within these facilities and work with physicians to develop appropriate care plans tailored to residents who have multiple chronic conditions like diabetes and congestive heart failure.

This model focuses on prevention and helps active seniors remain healthy and connected to their community, leading to a greater sense of well-being. Often, residents and the residential community monitor their neighbors' health and alert on-site clinicians about

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<sup>1</sup> Internal study conducted by VNS CHOICE for the 1999-2002 time period.

their concerns. Strong, long term continuous relationships are formed between residents and clinicians, who are familiar with a resident's care history. This model can be adapted to provide supportive service programs to rural and suburban sites, as well as to urban areas, by creating a "horizontal" NORC, whereby a nurse is assigned to a cluster of individual housing units, private homes and low-rise apartment buildings.

### **Solution 3: Experiment with Population-Based Care Management Models**

VNSNY annually provides services to over 10,700 diabetics and 4,500 patients with congestive heart failure and has begun to move toward more population-based models of care. It is involved in a partnership with the United Health Group to implement a Chronic Care Improvement Program for the Fee-For-Service Medicare population. For the thousands of costly, high-utilizing Medicare beneficiaries selected by Medicare, a risk assessment will be conducted. The model will combine "high-tech" and "high-touch" care and the highest risk groups will be assigned a care manager who coordinates targeted interventions and tele-monitoring services, and who monitors and communicates a patient's medical status with physicians. Vital to the success of the model will be physician involvement and the degree to which enrollees see themselves as partners in their care management.

### **Leveraging Technology:**

**Web-Based Communication:** As a next step after developing an electronic health record which clinicians can access on a mobile pen tablet, VNSNY is developing a physician web-based portal that securely shares patient medical and demographic data with physicians. A MD web-portal would allow physicians to electronically sign physician home health orders, a regulatory requirement that authorizes a patient's plan of care and orders for medications, laboratory tests, therapies and other services. Physicians could also communicate plan of care changes electronically and can make new referrals to VNSNY. Through another initiative, VNSNY and the Institute for Urban Family Health, a large primary care group practice operating in 13 locations, have been awarded a grant to develop an electronic exchange of information for patients that are shared between the two providers.

**Regional Health Information Networks:** Through a more regional approach, VNSNY is participating in a consortium of 20 providers to create a Regional Health Information Organization, or RHIO, in the New York area. The objective is to provide hospital emergency room physicians on-line access to a patient's clinical information that have been accumulated from previous visits to other

providers. The goals are to increase the speed of patient care in the ER and to reduce unnecessary costs.

These technology efforts have the potential to create “virtual” networks in areas where many providers will continue to practice and may eventually allow for the development of one medical record owned by the patient.

### **Conclusion**

Caring for the aging population, particularly those with multiple chronic conditions, present multiple challenges and opportunities. Strengthening home and community-based services will require innovation, experimentation with a range of management models, and greater application of and investment in technology. It will necessitate seeing the system through the eyes of the consumer and shifting more power to them, as well as building more enduring partnerships among providers, consumers, researchers and policymakers.



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We have been asked to pose innovative solutions to a public health problem that is fast advancing...an unprecedented number of seniors entering Medicare at a time when 1) health labor shortages move from serious to profound<sup>1</sup> 2) health care systems continue churning 3) consumers' trust in the medical establishment is eroding<sup>2</sup> 4) the spiraling national deficit creates a perception of insecurity around critical federal entitlements<sup>3</sup> and 5) other national priorities compete for Congressional attention. You have seen many statistics profiling this problem. The one that continues to draw my attention comes from a 1997 CBO report, appearing in an Urban Institute Briefing paper: *"Between 2010 and 2030, the over 65 population will rise over 70%, while under current law the population paying payroll taxes will rise less than 4%."*<sup>4</sup>

Solutions to this emerging crisis will necessarily involve many strategies, notably ongoing refinement of fiscal models, the dissemination of the electronic medical record, the application of disease management and telemedicine practices, the development of palliative medicine as a subspecialty, as well as improved communications regarding care preferences and plans with those at risk. Encouraged by Dr. Lynn to propose radical options, however, I would like to suggest a very specific one that seldom reaches the policy tables and is more radical in its conception than its implementation: **Extend hospice's palliative medical and care management competencies beyond care of the dying to care of chronically ill patients and their caregivers, allowing concurrent curative and palliative therapies.** This effectively moves hospice from a Last Scene to a Third Act Service. As hospice staff quarterback across ever changing care settings, critical information about patient treatments, reactions, preferences, values, needs and family context would be consistently available. Their attention to the patient's pain and suffering when it arises, not just in the last few weeks of life, would prevent tragic life closure.

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<sup>1</sup> American Association of Colleges of Nursing. Nursing Shortage Fact Sheet.  
<http://www.aacn.nche.edu/Media/Backgrounders/shortagefacts.htm>

<sup>2</sup> American Health Decisions, *The Quest to Die with Dignity*, Appleton, Wisconsin, 1997.  
p. 13.

<sup>3</sup> LJ Kotlikoff and S Burns, *The Coming Generational Storm*, Cambridge: MIT Press, 2004.

<sup>4</sup> *Policy Challenges Posed By the Aging of America*, Urban Institute Discussion Briefing, May 1998

There are important reasons to consider this:

1. Foremost, quality outcomes at the end of life are subject to hundreds of inflection points prior to a hospice admission. The literature is replete with examples of inadequate care leaving people in unbearable pain and anxiety-provoking shortness of breath prior to a hospice admission. The therapeutics should be provided when the needs emerge, regardless of prognosis, and when possible before they emerge, to prevent them.
2. Caregivers exhausted from the constant responsibility of care for dependent and distressed individuals, particularly when dementia is a comorbid condition, not only have difficulty with providing prescribed treatment and dietary regimens, their own mortality and morbidity is seriously affected. In a population based cohort study of 819 caregivers and non-caregivers aged 66-96, those caregivers who expressed strain in the tasks of caregiving, had a 63% higher risk for mortality than non-caregiving controls, as well as increased incidence of depression, greater cardiovascular reactivity, lowered immunity and slower wound healing.<sup>5</sup> Because the patient and family are the therapeutic unit in hospice care, factors that contribute to caregiver burden are routinely assessed and substantially reduced. While surviving spouses die at twice the normal rate during the first year of bereavement, in a study conducted by Christakis and colleagues involving 35,000 couples, recently bereaved spouses were found less likely to die within 18 months after their partner's death if the patient had received hospice care.<sup>6</sup>
3. Older people, nonwhites, immigrants and those with low incomes, the populations who largely rely on Medicare, Medicaid, and the State Children's Health Insurance Program for their health care, are disproportionately more likely to have trouble reading and understanding written information resulting in higher health care costs. An estimated 60-80% of English-speaking seniors have been found to have inadequate health literacy.<sup>7</sup> Medicaid patients reading below the third grade level were found to have average annual health care costs four times (\$12,974

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<sup>5</sup> R Schulz and SR Beach, "Caregiving as a risk factor for mortality," *JAMA* 282 (1999), 2215-19.

<sup>6</sup> NA Christakis and TJ Iwashyna, The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses, *Social Science & Medicine* 57 (2003) 465-475

<sup>7</sup> JA Gazmarian et. al., "Health literacy among medicare enrollees in a managed care. organization." *JAMA* 281, 545-551. 2/10/99.

compared with \$2,969) those of the overall Medicaid population.<sup>8</sup> The availability of a hospice nurse 24 hours a day for advice, interpretation of new information or an emergency visit is highly valued by poorly comprehending caregivers.

**Hospice Care Management is a Potential Solution to Unrelieved Patient Distress, Discontinuity of Care, Caregiver Burden and the Economic and Therapeutic Consequences of Low Health Literacy**

There are 3,300 hospices across the country uniquely licensed to cross settings where care is provided. Once the patient has signed an informed consent for hospice care, their interdisciplinary teams and volunteers follow them into hospitals and nursing homes as well as their private residences, SRO's, prison cells or shelters. Hospice staff address problems that are commonly experienced during the final phase of illness, but often these problems have been a part of the prior and longer phase of their disease process. Unrelieved, such persons tragically see themselves engaged in prolonged dying rather than living healthy, with illness. Unrelieved, elderly caregivers are burdened with the fear that their commitment to their companions will be trumped by their fatigue and weakness and their loved ones will suffer as a result of their actions. Unrelieved, patients and families with low health literacy experience frequent hospitalizations and emergency room visits, while others avoid necessary care not knowing they are eligible for Medicaid services.

**Performance of Value to All Stakeholders**

Prior to the development of any types of formal outcome measures, hospices were successful in areas critically important to terminally ill patients and their caregivers. As a result hospices became the recipients of significant national philanthropy, strong community and volunteer support and have experienced very low levels of litigation while managing the care of exquisitely ill patients in environments over which they have limited control. These are unusual but meaningful social indicators of service value beyond customarily positive satisfaction surveys.

When hospices serve patients in nursing homes, significant achievements are made. Care enhancements, such as improved pain assessment and treatment and decreased use of physical restraints, have been documented and are experienced by nonhospice patients as well as those served by the hospice staff. Hospitalization rates plummet. Miller and colleagues compared 9,202 nursing home residents in five states who enrolled in hospice

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<sup>8</sup> BD Weiss, et al. "Illiteracy among medicaid recipients and its relationship to health care costs." *Journal of Healthcare for the Poor and Underserved*, 1994; 5:99-111. Cited by Gazmarian.

between 1992 and 1996 and who died before 1998 to 27,500 residents who did not receive hospice care or were in facilities where it was not available. The researchers found that 24 percent of hospice and 44 percent of non-hospice residents were hospitalized in the last 30 days of life. However, for residents enrolled in hospice for the entire last 30 days of life, rather than just a portion of that time, only one percent was hospitalized.<sup>9</sup>

The National Hospice and Palliative Care Organization and the National Hospice Work Group have worked closely with CMS and JCAHO in constructing simple client-based performance measures that have common utility to consumers, payers and clinicians. These performance measures were based on the end-result outcomes of care defined in “*A Pathway for Patients and Families Facing a Terminal Illness*”<sup>10</sup> and have recently been recommended for implementation in the proposed revisions to the Hospice Conditions of Participation for Medicare. The outcome domains were Comfortable Dying, Safe Dying, Self Determined Life Closure and Effective Grieving.

The following outcomes were reported in the beta (n = 1409) pilot study of these measures:

- 1/3 of patients admitted to the participating hospices were admitted in pain. Of those admitted in pain and still able to report at the end of 72 hours, 82% reported their pain had been brought to a comfortable level. Scores differed among programs, indicating the measure was sensitive as a benchmarking tool.
- 95% of those who said they did not want to be hospitalized as their condition worsened, were not hospitalized.
- 99% of those who said they did not want CPR if their heart or lungs stopped working did not get CPR.
- In health care literature, improvements in caregiver confidence have been linked to improvements in caregiver competency. When asked, “*If you cared for the patient at home, did hospice increase your confidence to safely care for your loved one as death approached?*” family members responded “yes” 95% of the time.

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<sup>9</sup>SC Miller, P Gozalo and V Mor. Hospice enrollment and hospitalization of dying nursing home patients, *American Journal of Medicine* 2001; III:38-44

<sup>10</sup>T Ryndes et al. *A Pathway for Patients and Families Facing Terminal Illness* (Alexandria, VA: The National Hospice Organization, 1997).

- 93% of family members acknowledged they received effective support from hospice in preparing for death and 95% acknowledged effective support from hospice in coping after the death.

**Conclusion:**

Since its inception, the pioneers of the North American Hospice Movement have valued innovation. Passed into law by Congress in 1983, the Medicare Hospice Benefit was constructed from a demonstration study of white middle class adults with cancer. Early leaders quickly adapted it to widely different populations in need: children, people with HIV/AIDS, CHF, renal disease, ALS and other noncancer diseases. Cobbling local resources together they serve complex patients in throughout the country including hard-to-serve inner city and frontier locations. As the “new kids” in the health care sector they have few traditions to overcome, hence are interested in how the application of telehealth technologies and principles of disease management might improve the efficiency and effectiveness of their care. It is consistent with this spirit of ongoing innovation that care of those facing imminent death might reasonably be considered the *first* expression of a set of core competencies that should be available to patients and their caregivers much earlier in their illness, with positive effects on quality of life and end of life outcomes and probable positive economic consequences.



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**The POLST Paradigm:**

**States' Solutions to Honoring End-of-Life Treatment Preferences**

Good morning, I am Dr. Susan Tolle, a practicing internist and Professor of Medicine in the Division of General Internal Medicine and Geriatrics at Oregon Health and Science University (OHSU). As Cornelia Hayes Stevens Chair and Director of the Center for Ethics in Health Care at OHSU, I partner with other healthcare leaders to design and implement statewide systems for improving end-of-life care. I am speaking on behalf of the National POLST Paradigm Task Force and would like to discuss a problem, a solution, and a recommendation for your consideration.

**The problem**

Let me begin with a case that presents the problem and the solution. Martha Johnson is an elderly woman with advanced dementia who lives in a skilled nursing facility. She previously completed an advance directive requesting “do not resuscitate” status and no intensive care. She has also completed paperwork appointing her daughter to make medical decisions. One Saturday night she is overcome with a fever, cough, and shortness of breath. Her facility is unable to reach her daughter and transfers Mrs. Johnson to the nearest hospital where she is admitted to the intensive care unit and placed on a ventilator. On Monday, Mrs. Johnson’s daughter learns what has happened and demands to know why the nursing home orders were ignored.

Why did this happen? Completing an advance directive or living will is often not sufficient to ensure that patient wishes to have or to limit care will be consistently respected. Advance directives are general statements of patient preferences but need to be carried out through specifications in medical orders when the time comes. Even medical orders have limited authority outside of the institutions in which they are written. For example, physician orders at the nursing home usually have no authority in the ambulance or at the hospital.

**The solution**

Mrs. Johnson needed a document with medical orders that were consistently followed at each step of her care, from the nursing home to the ambulance to the emergency room to the intensive care unit. This is what the Physician Orders for Life-Sustaining Treatment (POLST) form accomplishes. The POLST form is a standardized set of medical orders

developed by a statewide coalition of citizens, healthcare professionals, healthcare agencies and organizations representing hospice, hospitals, emergency medical services, primary care providers, long-term care, and aging services. The POLST program was developed in Oregon and has been implemented in parts of 15 states (see [www.polst.org](http://www.polst.org) for further details). POLST orders are primarily intended for use by persons with advanced chronic illness who wish to turn some aspects of their advance directives or advance care plans into action at the present time.

### **The POLST Program**

Key elements of the POLST program are:

- **A protocol.** Policies and procedures for asking about patient preferences, completing a physician order (POLST form), transferring it with the patient across healthcare systems, and implementing it at each step in the transfer process.
- **A form.** This is a standardized order form, signed by a physician, detailing patient wishes to have or to limit specific medical interventions such as CPR and mechanical ventilation. The form is brightly colored and placed in an obvious location so that medical personnel can easily find it.
- **Education** for all parties involved – patients, families, healthcare professionals, and health systems.
- **Revision** of the materials at a statewide level to incorporate regional, cultural, legal, and other differences.
- **Ongoing research** about the experiences of different states and regions currently utilizing the POLST program.
- **Dissemination** of data and resources to other states and regions wishing to adopt the POLST paradigm.

We have strong evidence that this approach really works. Persons in Oregon using the POLST virtually always have their decisions honored, even during transfer to a hospital at the time of a serious complication. Persons living with serious chronic illness are advised to have a POLST with them at the time of any serious exacerbation.

### **Recommendation**

State leaders should encourage implementation and modification of the POLST paradigm at the state level and share these experiences on the [www.polst.org](http://www.polst.org) website. Each state can proceed with respect to its regional and cultural differences before considering broad implementation at the federal level. The ultimate goal of the POLST program is to assure that the wishes of persons with advanced serious illness are honored and respected.



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My name is Gerard F. Anderson, and I am a professor at Johns Hopkins University. This morning I would like to discuss the cost of treating people with chronic conditions, especially those in the Medicare program, and how the Medicare program needs to be restructured to be responsive to their needs.

**Where are Medicare Dollars Currently Being Spent?**

Eighty-three percent of Medicare beneficiaries have at least one chronic condition. As additional diseases are diagnosed, expenditures and the probability of an adverse outcome increase rapidly. Any policymaker who is considering the modernization of Medicare must recognize that the 23 percent of beneficiaries with five or more chronic conditions account for 68 percent of the program's spending. In addition, the treatment of these beneficiaries is likely to remain a high-cost item until they die, since every year they see an average of 13 physicians and fill an average of 50 prescriptions. They are also the beneficiaries who are most likely to have a preventable hospitalization and have the highest out-of-pocket spending because of the gaps in coverage and cost-sharing arrangements.

**Medicare was a Program for People with Chronic Conditions –But Did Not Know It**

When the Medicare program became operational in 1966, its primary orientation was the treatment of acute, episodic illness. The design of the program's benefits, coverage policies, payments to providers, and criteria for determining medical necessity were all oriented toward the treatment of acute diseases. Medicare retained this orientation of the next 40 years in spite of the growing number of Americans with chronic conditions. The Medicare Prescription Drug Improvement and Modernization Act of 2003 was an important first step in the reorientation of the Medicare program toward the care of patients with chronic conditions. Additional changes, however, will be necessary if the Medicare program is to be truly responsible to its millions of beneficiaries who have chronic conditions, especially those with multiple coexisting illnesses.

**Out-of-Pocket Spending**

One change is to restructure the cost-sharing arrangements in fee-for-service Medicare. Out-of-pocket spending by Medicare beneficiaries increases by an average of nearly \$400 with each additional chronic condition. The current cost-sharing arrangement, such as the 20 percent coinsurance for physician visits or gaps in the prescription drug benefit are especially onerous to beneficiaries with multiple chronic conditions because these people are the highest users of medical services. One possible solution is an out-of-pocket

maximum. Most private insurers place a limitation of the patient's out-of-pocket expenses, and Medicare could adopt a similar approach.

### **Care Coordination**

For Medicare beneficiaries with five or more chronic conditions, who see an average of nine physicians on an outpatient basis and four hospital-based physicians during the year annually care coordination is especially important. The Medicare program should be required to explicitly pay for care coordination. Each beneficiary with five or more chronic conditions would designate a care coordinator who would be required to communicate with all other clinicians on a periodic basis and help coordinate services.

### **Medicare Payment Rules**

Important changes in Medicare's payment systems will be needed. Fee-for-service payments will need to be restructured to encourage clinicians to work cooperatively, to encourage additional means of communication, such as e-mail and to permit doctors to see a group of patients at once and allow other providers to participate in, and be reimbursed for the care of patients. Payments to managed-care plans will need to cover the full expected cost of care for beneficiaries with multiple chronic conditions – something that the current system does not do.

### **Obstacles**

There are several problems to overcome before Medicare can implement any of these recommendations in the next round of program reforms. Some of these proposals are likely to increase the costs of Medicare, at least in the short run. However, spending could be lowered by reducing the number of hospitalizations, drug interactions, and duplicate tests. The second problem is the potential for fraud and abuse. The fraud and abuse concern is how to determine whether services are actually being provided, especially for activities such as e-mail communication. The third problem is how to demonstrate improvement in health outcomes. Both physicians and beneficiaries will need to be convinced that the reforms result in better clinical outcomes. The fourth problem is the unwillingness of some clinicians to participate in the reforms. In some ways, the further consideration may be the most important obstacle. Costs can be lowered, fraud and abuse minimized, and outcomes improved only if a high percentage of clinicians perceive that Medicare's new orientation is improving outcomes.

Medicare is becoming a program for people with chronic conditions. However, we have just begun the journey.

**Panel 3**  
**Motivating Change – Information and Advocacy**

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My name is Donald Schumacher, and I am President and CEO of the National Hospice and Palliative Care Organization (NHPCO), which is the nation's largest nonprofit organization providing leadership for the field and representing hospice and palliative care programs and professionals. I also serve as President of the National Hospice Foundation and the Foundation for Hospices in Sub-Saharan Africa.

Hospice began as a grassroots movement in the U.S., shedding new light on the needs of the terminally ill and their families. The enactment of the Medicare Hospice Benefit in 1982 created a significant care coordination model that, this year, will support over 1 million individuals living with life-limiting illness, and their families. As hospice considers both the patient and the family to be the unit of care, tens of millions benefit from this service every year.

While originally designed as a benefit tailored to cancer patients, more and more individuals with non-cancer diagnoses are receiving hospice care at the end of their lives. Because of the unpredictable trajectory of many non-cancer diseases, the required six-month prognosis for admission under the Medicare Benefit, and other factors affecting hospice referrals, the median length of stay in hospice programs remains low. Due to late referrals, far too many patients and families fail to benefit from the wide range of services hospice has to offer. One of the most frequent comments hospice providers hear from the people they serve is that they wished they had been referred to hospice sooner. Finally in hospice, all of their needs are taken seriously: including bed baths and medications, spiritual counseling and support for family caregivers— it's all in one package.

Hospice and palliative care clinicians prioritize these changes in practice and policy: extending the benefits provided to the seriously and terminally ill to cover more people for longer periods; reducing the family caregiver's burdens; and educating patients, families, and the public generally about the need for making plans in advance to shape the course of serious illness at the end of life.

NHPCO sees three specific strategies for leveraging improvements, and we have launched initiatives in each arena:

1. Public education and consumer empowerment: Ordinary citizens need to know what is at stake and how they can take action. Through NHPCO's Caring Connections initiative, supported by the Robert Wood Johnson Foundation, hundreds of thousands of people are receiving information to help them plan for end-of-life care before they

face a crisis. State-specific advance directives, information about care options and advance care planning, and materials about hospice and palliative care are provided freely. Over 600,000 people have visited our consumer Web site; more than 500,000 have downloaded advance directives since February 1, 2005. Opportunities abound for this work to expand. Medicare's consumer Web sites could better inform people of their likely course and options for care. Political leaders could formulate reforms around the needs of this population. Broader consumer groups could galvanize around family caregiver and home care workforce issues.

2. Professional education across the health care continuum: Most health care providers have little opportunity or inclination to learn how to participate in optimal care arrangements. As the population ages and so many more people live with eventually fatal chronic illnesses, skilled and reliable professionals are central to any care arrangement. NHPCO has been addressing this as energetically as possible: teaching health care providers how to provide optimal palliative care to people in the last years of life through educational conferences, the Hospice Managers Development Program, and our Audio Web Seminars. We provide education content to Web MD and Medscape. Again, the opportunities for others to build upon and leverage this work are abundant. Federal funding for training of physicians and nurses could carry a requirement to learn how to work in teams and in homes and to value continuity and comprehensiveness rather than just specialization. NIH and AHRQ training and research funds could include concerns of this last phase of life. As a society we haven't done nearly enough to develop professionals competent in all aspects of caring for people in the last years of life.
3. Public policy initiatives: Federal policies are dominant in shaping the nature of care for serious chronic illness. Medicare, Medicaid, the VA, and other federal agencies pay for the overwhelming majority of the services. The dysfunctional patterns of payment, the lack of focus on caregivers, and the regulatory environment regularly get in the way of effective, efficient care. NHPCO has worked to expand access to hospice/palliative care. At present, we propose these as the high-leverage opportunities:
  - Concurrent Care: Establish a multi-site pilot project that requires delivering palliative care simultaneously with life extending and/or disease modifying treatment, from the onset of serious chronic illnesses such as cancer and heart failure. The project should address comprehensive needs and ensure coordination across the continuum from onset of serious illness to death.
  - Payment Outliers: Establish a demonstration project to learn whether higher payment for short stays and additional payment for new therapies/high cost drugs would enhance the impact and availability of hospice services.

- Rural: Implement projects designed to learn optimal models of improving telemedicine, staffing, and enhanced transportation options for rural areas.
- Non-Government Demonstrations: Utilize the commitment of insurers and pension providers to support innovative demonstration projects, such as the current Palliative Care initiatives of the Aetna Corporation.
- Pediatrics: Support the development of innovative children's hospice and palliative care pilot projects like the PACC waivers and demonstration projects.
- Hospice Consult: Many patients and families would benefit from an assessment and counseling opportunity with a skilled hospice or palliative care provider, early in the course of living with serious chronic illness. This would include psychosocial as well as medical consultation, with proper adjustment for end-of-life care specific activities, e.g. counseling and coordination of care in all settings.
- Hospice Information at Hospital Discharge: Require that hospital discharge planners provide Medicare beneficiaries with a list of hospices, as they are now required to do for home health agencies.

The success of hospice care is now being extended to non-hospice patients in many settings via the development of palliative care programs. These programs provide the care coordination, medical and psychosocial support, and bereavement opportunities often limited to hospice enrollees. The evidence thus far uniformly shows that these programs save resources and enhance care.

What began as a grassroots movement over 30 years ago has grown to be an integral component of the health care landscape, reflecting not only the highest quality of medical and psychosocial care but demonstrating humankind's capacity for and capability to provide compassion. Hospice is the only widespread innovation in Medicare services since the inception of Medicare forty years ago. Our programs have shown that excellent, reliable care for very sick people is not only possible, but it is possible in every part of the country. Patients and families are so grateful to have finally come into care that is comprehensive and will stay with them through all that will happen. The principles of hospice are available to apply elsewhere, and hospice programs themselves could expand, but building on this success, or even sustaining it, requires that the nation develop data and policy that address the phase of life when people live with serious illnesses. This society needs to build on the strength of hospice innovation and hospice and palliative care programs and to develop policies that support family caregivers, ensure symptom management, guarantee continuity through serious illness, and allow life closure with meaningfulness and comfort. NHPCO and our members are committed to this work, and our insights and resources provide the exploration of this terrain. With the aging of the population, health care policy should build on this solid foundation. Federal agencies should monitor outcomes and fund innovations, leaders should have an annual report on progress, and we should all participate in a campaign to build the care system we can rely upon when we need it most.





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President Ronald Reagan, in his farewell letter to the nation, called the journey he was beginning the “long goodbye.” A long goodbye is what many Americans experience today. Death is no longer likely to occur as the result of sudden infection or injury. Rather, most Americans die gradually, in old age, and at the end of a lengthy period of chronic illness. A demographic shift is occurring that will increase the number of seriously ill and dying people at the same time as the relative number of caregivers decrease.

My remarks will identify five areas of caregiving near the end-of-life that require our attention. Caregiving plays a critical role at the end of life and caregiver education, support, and respite are paramount to helping families keep older, chronically ill loved ones at home.

The following are what I call the five C’s of caregiving:

1. **Communications** - Increased communications between individuals and systems is needed to improve understanding and coordination of care. The recent public debate about the Schavio case underscores the need for clear on-going communications. Advance care planning requires ongoing dialog within the family and with care providers, and must follow the patient across health care settings. Electronic medical records offer a vehicle to improve communications and the continuity of care.
2. **Choice** - Our nation values freedom of choice. Respect of end-of-life care choices should be a central value in caregiving. Patients and their caregivers want to be asked about preferences, given options and be supported in their decisions. The patient and caregivers’ choices should be reflected in the medical record and should be readily available across health care settings and systems. Unfortunately, that is not the standard today.
3. **Continuity of Care** - The end-of-life process includes numerous transitions: physical, emotional, financial and spiritual for both patients and caregivers. There are also transitions in the health care system that the patient and caregivers face, exacerbated by the lack of continuity across systems of care, challenges to the social support networks and unshared clinical information. Care plans and care teams need to follow the patient across systems. Health payers should incentivize provider teams that follow a patient across systems of care.

4. **Continuing education and training** is needed across the continuum of care. The United States Bureau of Labor reported that by the year 2010, less than five years from now, more than 1 million nurses will be needed. We must better educate professional, para-professional and family caregivers. Leadership and mentorship programs should be developed to recruit and retain the workforce needed to care for an aging society. Family caregivers, who provide approximately 80% of the care for chronically ill and dying loved ones, need to be prepared to competently carry out their role. They need timely, appropriate, ongoing education and training especially regarding activities of daily living and advocacy for their loved ones.
5. **Changes in legislation, regulation and policy** - One place to start is to develop, test and evaluate new models of end-of-life care for Medicare beneficiaries designed to overcome barriers to the utilization of the current hospice benefit. Currently, the national median length of stay in hospice is approximately 3 weeks and 10% of patients enroll in the last day of life. Clearly we can do better.

When I travel around the country and speak about our foundation's work in end-of-life, I often hear personal family stories that describe a death gone wrong. The circumstances are always unique to the family, but the anguish and painful memories are vivid and alive, even if the death occurred decades ago. Dame Cicely Saunders said, "How people die remains in the memories of those who live on." I call on the delegates of the White House Conference on Aging to join together in a movement to address end-of-life caregiving issues. We are all stakeholders in making the process of the last journey compassionate and caring.

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Good Morning. My name is Dr. Judith Black, and I'm the medical director for senior products at Highmark Inc., a Blue Cross and Blue Shield health plan in Pennsylvania, and a practicing geriatrician.

Americans are living longer. At the turn of the 20th century, the average life span was 47 years. In exchange for the increase in life expectancy, more Americans today live with chronic conditions and dementia, facing a gradual decrease in the ability to function independently. This change has led to an increase in the amount and types of care required in the last years of life.

As a representative of the fourth largest Medicare HMO in the country and one of the first insurers to offer Medicare supplemental insurance, I'd like to share what I have learned.

During my tenure as medical director, I have identified three major problems that shape the quality of care of members over the age of 65. Too many members are on medications that could be harmful. Members too often receive fragmented care. And too many don't receive the care they want at end-of-life.

As a health insurer, here are some actions we took to address these issues.

Working with 80 network physicians that care for our Medicare HMO members, we implemented a pilot to address inappropriate drug use in the elderly. Highmark developed drug profiles that showed physicians the number and types of inappropriate drugs prescribed, using nationally recognized criteria and poly-pharmacy rates. We worked directly with the practices to implement behavior-change strategies using patient specific data, peer comparisons and quarterly feedback. At the end of the one-year pilot, there was a 17 percent decrease in the number of "rarely appropriate" drugs prescribed and overall these physicians prescribed 10 percent fewer potentially inappropriate medications. We are also underwriting the cost of e-prescribing for several practices.

Transfers among care settings are common for the older adult with complex acute or chronic conditions. While their well-being depends upon seamless coordination of care across care settings, that is not the common experience. One solution is developing and implementing an electronic medical record that is accessible to all providers, from primary care physician to acute care hospital. Through our physician incentive program, offices with an electronic medical record can earn additional points towards their incentive payment.

To encourage effective transfer of information and ensure accountability for patients transitioning between care settings, Highmark initiated a pilot with two of our network hospitals and surrounding nursing homes to improve care transitions.

On-site case managers through our SeniorCareBLUE program ensure that Medicare Advantage members who live in an institutional setting receive appropriate care. The program has increased immunization rates and encouraged the use of the Physicians Orders for Life Sustaining Treatment while slowing the rise in care costs.

We encourage our members, their families and providers to view advance care planning as a process to ensure that individuals receive the care they want – or do not want – if they become unable to speak for themselves. For the past several years, Highmark has provided network primary care physicians with tools to help facilitate advance care planning discussions with their patients. We have also worked with area nursing homes to raise awareness of advance care planning and encourage these facilities to adopt the POLST form as the standard tool for documenting end-of-life treatment choices. As the use of POLST is limited in Pennsylvania, as a solution our health plan has joined with community leaders and created a coalition that is successfully building support to enable enactment of legislation that will assist providers in complying with patient wishes.

Through a pilot program with a local health system, structured counseling was offered to community residents who had an estimated six to eighteen months to live to address the issues that emerge during advanced illness. The results were significant. Of the program's participants, 70 percent enrolled in a hospice program – compared to 21 percent for the rest of our members.

Based on my experience as a medical director for a major health insurer, here are some solutions to improving quality of care across the health care continuum for older adults:

- Encourage members to select a “medical home,” and arrange clinical services to expect to be that “medical home.” Older adults with serious chronic illnesses need to coordinate their care through a designated physician capable of 24/7 coverage, rapid response to the home, and comprehensive management of services – whether or not they are in a managed care plan.
- Establish a national standard of care for the frail elderly that focuses on such issues as fall risk, medication management and discussing advance directives. The RAND Corporation's Assessing the Care of the Vulnerable Elders (ACOVE) measures are a good place to start by establishing a pay-for-performance program for physicians that provides care based on these standards. The “Welcome to Medicare” examination should include advance care planning, and transfers among settings of care should precipitate review and re-documentation of care plans.

- As reimbursement practices evolve, explore paying physicians for the increased time spent providing care to the elderly by risk-adjusting payments.
- Risk-Adjust Medicare Advantage payments by complexity and severity of illness, and frailty (not just diagnosis) so that insurers and providers can afford to gain a reputation for excellence in providing care for the most complex and disabled elderly.
- Encourage adoption of an electronic medical record across the health care continuum so that all segments from the primary care physician to nursing homes have access to the same patient information.

Breakdown barriers to advance care planning. Encourage states to adopt the POLST program and share the experience on the POLST website, [www.polst.org](http://www.polst.org). The ultimate goal of the POLST program is to assure the wishes of patients with advanced serious illness are honored and respected— even if they are transferred across care settings.



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Thank you very much for the opportunity to put the concerns of seriously ill elderly and their families before the White House Conference on Aging. I am Anne Wilkinson, a gerontologist doing research on caregiving and quality of care and leading quality improvement activities for clinical programs that are trying to forge improved strategies for care.

Most people live long and healthy lives now, but no matter how carefully we protect our health, eventually each of us will become sick, frail, or disabled from one or more conditions that ensure ongoing illness through to death. At this time of life, the care system has to make sense. People cannot enjoy the last of life if they must fight their care system. For elderly persons and their family members, the services that the community makes available should be comprehensive, reliable, and readily accessible while reimbursement and payment policies for these services should be sensible.

Seamless coordination of existing medical care and supportive services is an essential hallmark of quality care for people with advanced chronic conditions – but even that would not really be the best that we could do. When we must live with serious and eventually fatal conditions, the best arrangement would be to have clinicians who stay with us across time and settings, and to ensure that the services most needed actually are available. A workable continuum of care has to reflect the priorities and needs of the population served, which are quite different from those of healthier people earlier in life. Comprehensive services by responsive and enduring clinicians would make such a difference, compared to the costly, error-prone, frightening patchwork of uncoordinated services that sick people must now shuttle among.

While most people would welcome improvements in transitions and services, those who most urgently need reliability across time and setting are those living with advanced chronic illnesses, including those who are:

- Dependent for the rest of his or her life upon direct help from another individual or assistive devices in order to live at home;
- Nursing-home residents;
- Admitted to a hospital or an emergency department multiple times due to exacerbations in serious underlying illnesses;
- Unable to advocate for themselves; or
- Diagnosed with a serious, eventually fatal, illness.

Except for the more integrated care systems such as staff-model managed care or the Veterans Health Care System, patients living with serious chronic conditions usually endure a patchwork of uncoordinated services, each engendered to address some prior gap or to allow practitioners to be paid. Most current healthcare services conform closely to the payment system and to the

habits of the providers. No deliberative, authoritative process exists to shape the service arrangements around the needs of those served. No one assumes responsibility for implementing or monitoring comprehensive care over time. Rarely does one see a substantial commitment to shaping care around preferences and priorities of the patient and family. The situation is rife with inefficiency, error, duplication of tests and services, gaps in needed services, and unreliability for patient and family.

**What should we have instead?** Simply put, people living with serious chronic conditions and their families should be able to count upon services that are essential to living comfortably and meaningfully through to the end of life, incorporating their own individual and cultural perspectives, and these services should be reliable, high quality, and entail costs that the community can sustain while serving all in need.

**How can we achieve this?** We can assure our own futures, and the futures of our families and neighbors, by promptly taking strong measures to engineer continuity in delivering services that are closely tailored to the priorities of the populations affected. While 83% of Americans die while covered by Medicare and the average person is already sick with their fatal condition three years ahead of death, the number of patterns of care that would suffice to serve most such people seems to be just three. Some people are substantially ill for only a short time, perhaps a few months, and they need aggressive symptom management and family support during that time, often in hospice care. Another group have badly damaged major organ systems – hearts, lungs, livers, kidneys, and so forth. Their fragile state of health leads to repeated hospitalizations, and optimal care aims to prevent those exacerbations and to ensure that the final overwhelming illness is handled in accord with the patient’s preferences. The last and largest group lives with frailty and dementia for a long time, and most prominently needs support of family caregivers and eventually reliable institutional care.

The major leverage in reform is to identify these populations and to arrange payment and practice patterns so that only continuity providers with services that match the population will be able to make a comfortable living serving this population. The current standard of episodic care marked by errors during transfers and unreliability for patients and family caregivers should be seen as so substantially second-rate as to be unworthy of sustaining. Once a patient has passed a threshold of severity of illness in any one of the three trajectories, evaluation of quality and payment policy should require continuity, responsiveness, symptom relief, family support, and advance care planning, as well as evidence-based medical interventions.

## RECOMMENDATIONS

The panelists and others have developed these specific recommendations for consideration this morning.

**Recommendation 1:** Pay more for services that provide comprehensive longitudinal care, and less for uncoordinated services.

**Solution 1-a:** Once a beneficiary is this sick, frail, or disabled, Medicare should pay current aggregate payment levels only for medical services that continue with patients across settings and time, through to death. Any uncoordinated, fragmented care is deficient and should receive discounted reimbursement.



**Solution 1-b:** For providers of high value care to this very seriously ill population, Medicare and Medicaid should set risk adjustment rates for managed care and care coordination fees for fee-for-service providers that reflect the real costs of providing care as well as meeting the need for flexibility in the configuration of the services delivered.

**Solution 1-c:** Services for this seriously chronically ill population through any other public funds should be tied to the service provider participating in and complying with regional planning that builds from the priorities of the affected people and ensures that the community is correcting gaps, duplications, and inappropriate services.

**Recommendation 2:** Require all critical elements of optimal patient care. Clinical service providers who cannot do these things should not be regularly providing care to this population.

- (1) Inclusion of at least medical, nursing, and psycho-social providers to work with patient and caregivers to formulate, implement, evaluate, and revise a comprehensive plan of care;
- (2) Requirement that plans address, at a minimum, future care issues and needs such as naming a proxy decision-maker, deciding whether to forgo emergency interventions, and setting out conditions for transfer to hospital;
- (3) Mobilization of most routine services to where the patient is: at home, congregate living facility, or nursing facility;
- (4) Adherence to evidence-based standards and guidelines for treatments and services;
- (5) Delivery of ongoing education, training, and support of patients and caregivers for self-management;
- (6) 24/7 telephone access to appropriate clinical help, always with access to the patient's record;
- (7) Rapid response by appropriate clinicians for urgent situations at home; and
- (8) Implementation of continuous quality improvement to ensure reliable excellence.

**Solution 2:** These hallmarks of quality care for those with serious chronic illness should be part of provider conditions of participation, certification of provider quality, reports of quality to the public, and payment for performance programs.

**Recommendation 3:** *Ensure continuity of patient records across settings and time.*

**Solution 3:** Medicare, the Veterans Health System, and other federal agencies funding electronic health record development should require the inclusion of standardized functional and social information, including advance care plans, that are accessible across multiple providers and care settings, including through the internet.

**Recommendation 4:** Sponsor intensive regional demonstrations of planning and care delivery.

**Solution 4:** Congress should authorize CMS, HRSA, ASPE, AHRQ, DVA, and other federal agencies to administer region-wide prototype and pilot projects to develop,

replicate, and ensure the rapid adoption of optimal models of planning, infrastructure, process, monitoring, and service delivery.

**Recommendation 5:** *Require an annual Federal report on the long-term care workforce, including family caregivers.*

**Solution 5:** Congress should require the Department of Labor to monitor and issue annual national and region-wide reports on the status of the long-term care workforce and on family caregivers as a workforce issue. These reports should address the potential effects of alternative policy decisions about the support of these workers.

**Recommendation 6:** *Require an annual report on progress toward reliable, sustainable longitudinal care arrangements for those who are sick, frail, or disabled in old age.*

**Solution 6:** ASPE (the Assistant Secretary for Planning and Evaluation in the Department of Health and Human Services) should report performance measures for the comprehensive, longitudinal coordination of care across the continuum, for the nation and for states and regions. ASPE should seek data and analysis from MedPAC, CMS, DVA, HRSA, AHRQ, NIH, CDC, and other agencies. This report should include specific attention to overcoming the barriers to continuity care arising among major federal providers and financers of health care: Medicare, Medicaid, DVA, HRSA, and DoD.

**Recommendation 7:** *Engender broad interest and activism among family and long-term-care caregivers.*

**Solution 7:** Sponsor engagement of affected persons and those who provide care in every plausible project and setting. Encourage formulation of potential policy agendas and vigorous public debate. Make good care for the last years of life into an active political agenda.

Many people balk at dealing with the fact that every one of us will get sick and die. It is a great boon for Americans to have the extraordinary historical opportunity mostly to grow old before becoming ill, but we also have the challenge of learning to live well, often for some years, with progressive and eventually fatal illnesses. If we learn to target this phase of life, to segment the services by trajectory and need, to require continuity and responsive services, and to support family and paid caregivers, we could all count on living comfortably and as meaningfully as possible. If we engineer those care arrangements efficiently, we can provide care we can count on when we need it most.

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I am Jon Fuller, Deputy Associate Chief of Staff for Geriatrics and Extended Care and Medical Director of the Home Based Primary Care Program at the VA Palo Alto Health Care System in Palo Alto, California. While listening today to the comments expressed by our expert panels, I inevitably put the faces of my many patients to the numerous stories and scenarios of health care delivery that were described.

One patient in particular came to mind. This gentleman is 80 years old. He has multiple medical problems including a 60-year history of rheumatoid arthritis. He has had three artificial hip replacements and 4 knee replacements. He has coronary artery disease with congestive heart failure and has had coronary stents placed in the past. He had aortic stenosis requiring aortic heart valve replacement and he has had numerous complications from the chronic treatment of his rheumatoid arthritis including intestinal bleeding, endocarditis, staph sepsis, and a chronically infected hip prosthesis. He takes multiple medications, 12 to be exact, amounting to 140 pills per week. He has battled depression off and on for several years. He is now developing a little dementia and his vision is failing. He is basically wearing out.

The gentleman is essentially writing the final chapter of his life. As with the majority of my patients, it is not easy to tell if he is in the first paragraph of that final chapter, whether he's entered the final paragraph of the final chapter, how long the chapter will be, or whether he is working on that final sentence. What is important to know is the current health care system and all the health care providers involved in his care are instrumental in the authorship of the final chapter, a chapter his remaining family members will read over and over again for the rest of their lives. It is also a chapter that each and every one of us will eventually write, or have written about ourselves.

The challenges of his care are numerous. He sees multiple medical providers juggling weekly clinic appointments of various specialists. His physicians cannot communicate fast enough given the number of providers involved in his care and the complexity of his treatment. He cannot drive so well anymore and his wife of 60 years is wearing out. He would certainly be institutionalized if it were not for his wife. He has had remarkable care throughout his life coupled with equally remarkable lapses in support. Most notably, he was provided emergency helicopter transport during an episode of chest pain at the rate of \$10,000 per hour but he was not provided a \$10 per hour caregiver to help him with housework, or meal preparation, or bathing and dressing. His existence has been one of residing tenuously at home with punctuations of emergency room visits and hospitalizations. Now with his memory failing, he cannot provide the

story to new clinicians he encounters and he doesn't have the energy or fight to ask for what he needs – a particularly perilous situation in a health care system based on self-advocacy.

I hope it is evident through this patient example how our recommendations today would build a health care system that would be much more responsive and appropriate to the chronic care needs of the majority of our patients. I believe it is a unique, proper, and obligatory opportunity for the WHCOA to address this looming health care crisis awaiting our baby boomer generation, including us in this room. Indeed, I believe this opportunity is consistent with the intent and spirit of why those before us developed the once a decade WHCOA's. The recommendations presented today are cross-cutting issues woven into the fabric of the annotated agenda as developed by the Policy Committee of the 2005 WHCOA. These recommendations are wholly consistent with the themes of "Planning along the Lifespan" and how to negotiate the final chapter and "The Workplace of the Future" as evident by the challenges facing our providers and caregivers. In addition, these events will have a profound impact on "Our Community" and the "Health and Long Term Living" of those in our community, which will be highly dependent upon the structure of the system we have to support ourselves. This structure will also be dependent on "Social Engagement" which will make this process more standard and mainstream as opposed to marginalized. Finally, the "Marketplace" will have a key role in making these recommendations come to fruition by incorporating the best of technological advances into our caregiving system.

Our gentleman mentioned in this scenario and those who will succeed him will have a much smoother existence through the implementation of the recommendations presented. It is crucial to establish comprehensive longitudinal care coordination incorporating appropriate timely access to care in the appropriate venue, multi-disciplinary care management, and attention to the informal care network including psycho-social, spiritual, and financial needs. Financial reforms and incentives must reinforce chronic care management through comprehensive continuity and not through the currently well developed and costly emergency response system of 911 and the acute care system of emergency rooms and hospitals. As the systems of care become increasingly complex, so should the information system. It is prime time to develop a nationally standardized readily and wirelessly available web based medical record system. Since the challenges facing us are large and complex, a single simple solution is not evident. This begs for the need of regionally based demonstration projects in our search for improvements in chronic care delivery. Lastly, national oversight is needed to assure attainment of quality, comprehensive, longitudinal care coordination and to report on the long-term care workforce and family caregivers as a workforce issue.

Finally, the patient I presented is not one of my patients; he is my dad. His caregiver is my mom. This is the health care system that is taking care of them and is the same one waiting to care for me. We can and must do better..

**White House Conference on Aging Solutions Forum  
Care Coordination Across the Continuum  
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